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Percutaneous Endoscopic Gastrostomy Placement Time in People with Cystic Fibrosis

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PERCUTANEOUS ENDOSCOPIC GASTROSTOMY PLACEMENT TIME IN PEOPLE WITH CYSTIC FIBROSIS

by

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ABSTRACT

Percutaneous Endoscopic Gastrostomy Placement Time in People with Cystic Fibrosis

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A retrospective chart review was conducted on pediatric patients at the Intermountain Cystic Fibrosis Center who had a percutaneous endoscopic gastrostomy (PEG) placed between 1993 and 1999. Height velocity improved significantly in the group of patients with a PEG placed; however, pulmonary function declined more significantly over time.

Questionnaires regarding attitude toward PEG placement were sent to patients enrolled in accredited cystic fibrosis centers in the mountain west region and to their parents. The overall response rate was 54.25% for the PEG questionnaire and 24% for the non-PEG questionnaire. Ninety-six percent of the patients with a PEG reported that weight was a problem at time of placement, and 91% reported weight gain after PEG placement. Sixty-four percent of the patients with a PEG reported that they would have a PEG placed if they made the decision again. Of the patients without a PEG, 60.7% thought a PEG looked bad, and 59.2% would be embarrassed to have a PEG. Forty-nine

percent of patients without a PEG expressed a lack of knowledge of the pros and cons of PEG placement and 35.4% had no opinion about their knowledge of PEGs.

PEG placement can be beneficial in improving nutritional status. Optimal time for PEG placement may be earlier rather than after pulmonary function has declined. People with a PEG have felt positive toward placement, and those without a PEG seem to lack knowledge about the pros and cons of PEG placement. (63 pages)

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Sarah Gunnell

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LIST OF SYMBOLS, NOTATION, DEFINITIONS

AZ- Arizona

BMI-body mass index

CBC-complete blood count

CF-Cystic Fibrosis

CFRD-cystic fibrosis related diabetes

CFTR- cystsic fibrosis transmembrane regulator

CO- Colorado

cyclic-AMP-

FEV_1- forced expiratory volume in 1 second

FVC- forced vital capacity

IBW-ideal body weight

ID- Idaho

IRB-institutional review board

MT- Montana

n - sample size

NM- New Mexico

p-observed significance value

PEG-percutaneous endoscopic gastrostomy

RDA-recommended dietary allowance

REE-resting energy expenditure

SPSS-Statistical Products and Service Solutions

UT-Utah

vs.- versus

CHAPTER I

GENERAL BACKGROUND AND INTRODUCTION

Definition and Complications of CF

Cystic fibrosis (CF) is the most commo1n genetic disease seen among Caucasians in the United States, affecting approximately 30,000 children and young adults (1). It is an autosomal recessive disease where both parents must contribute the CF gene for it to be manifest. One in 31 Americans is an asymptomatic carrier of the recessive CF gene (1). The expected life span of patients with cystic fibrosis has more than tripled over the past two decades going from median survival age of 10 years to median survival age of 32 years (2). Cystic fibrosis was once thought of as a childhood disease but has now carried over into adulthood. Adult patients aged 18 years and older accounted for 37% of the CF population in 1998 (2). With the extended life span of this population, long-term medical complications secondary to this multifaceted disease have been manifest.

The Human Genome Project has made great strides in the research of genetic diseases during the past 15 years, particularly with cystic fibrosis. The CF gene was the first gene identified by the Human Genome Project, and it has been used as a paradigm for the study of genetic diseases (3). This benchmark discovery has increased understanding of the genetic basis of CF, the basis of the biochemical defect, and the pathophysiology of the disease.

The cystic fibrosis transmembrane regulator (CFTR), a cyclic-AMP dependent chloride channel, regulates the transport of chloride ions across the cell membrane influencing water and electrolyte composition of sweat glands, pancreatic ducts,

heptabiliary ducts, and gastrointestinal glands. A genetic mutation of the CFTR causes faulty transport of sodium and chloride ions in the exocrine epithelial cells. This results in an abnormal accumulation of a viscous, dehydrated mucous that obstructs the respiratory, gastrointestinal, and genitouriniary tracts.

The primary clinical symptoms prior to diagnosis include respiratory distress, failure to thrive, steatorrhea, meconium ileus, and an increase of chloride concentration in the sweat. A sweat test result of sodium or chloride ion concentration greater than 60 mEq/L confirms diagnosis (4). The median age of diagnosis is 6 months and, and the mean age of diagnosis is 3 years (2).

The prognosis of CF is largely dependent upon pulmonary status. A decrease in lung function contributes significantly to the complications and debilitating health seen in CF. The obstruction of the airway epithelial cells results in bronchiolitis and increases susceptibility to infections such as *Pseudomonas aeruginosa* that destroy the lung. Seventy-six percent of the deaths reported to the Cystic Fibrosis Foundation Registry in 1998 were attributed to cardiorespiratory complications (2).

Another major complication of CF is pancreatic insufficiency. Pancreatic insufficiency is found in approximately 85% of patients with CF, and a decrease in pancreatic function is found in all patients with CF (2). Pancreatic secretions of water, biocarbonate, and digestive enzymes decrease substantially causing malabsorption and maldigestion of proteins, fats, and complex carbohydrates. A decrease in the production of trypsin results in a reduction of the hydrolysis of proteins into peptides and amino acids, and a decrease in the production of lipase results in a reduction of the hydrolysis of

deficiency, approximately 93% of patients with CF use pancreatic enzyme replacement therapy (2). Dosage of pancreatic supplements is determined on an individual basis due to variation in diet, intestinal pH, and anatomy and physiology of the gastrointestinal tract.

As the disease progresses, more clinical manifestations related to nutrition decline and deterioration of lung function present themselves. People with CF are at higher risk for digital clubbing, nasal polyps, delayed onset of puberty, decline in growth, decreased tolerance to exercise, liver disease, osteoporosis, pancreatitis, peptic ulcers, and diabetes. Optimal nutrition has been found to prevent or delay the onset of these complications.

Nutrition Effects on CF

Malnutrition is a common complication of people with CF. According to the Cystic Fibrosis Foundation 1998 Patient Registry, 22.5% of patients with CF fall below the fifth percentile for weight and 17.9% fall below the 5th percentile for height (2). Approximately 58% of those patients below the fifth percentile for weight have severely compromised pulmonary function (2).

Improved nutritional status is positively correlated with increased longevity, pulmonary status, growth, stature, and age- appropriate onset of puberty. Research conducted on males with CF between the ages of 13 to 17 years at the Children's Hospital of Pittsburgh Cystic Fibrosis Center identified nutrition and pulmonary function predictors of delayed puberty. It was reported that adolescent males with CF were more likely to have delayed puberty if they had weight $\leq 10^{th}$ percentile ($p<0.001$), height $\leq 25^{th}$ percentile ($p<0.05$), or BMI $\leq 25^{th}$ percentile compared to males with weight and height

percentile ($p<0.05$), or BMI $\leq 25^{th}$ percentile compared to males with weight and height greater than the 10^{th} and 25^{th} percentiles (5).

Another 3-year prospective study of growth, nutritional status, and body composition in children with CF showed slower rates of growth in boys with CF compared to boys without CF. Height for age z-scores (HAZ) decreased in children with CF and remained constant in children without CF. Boys also gained less fat mass and less fat-free mass than the controls. The authors concluded that children with CF grow at a suboptimal rate (6).

The development of diabetes in patients with CF is also associated with undernutrition. According to the CF Registry, 14.2% of the patients 18 years and older in 1998 had CF related diabetes (CFRD) that required insulin therapy (2). CFRD has similar characteristics to type 1 and type 2 diabetes; however, it has unique factors related to CF including undernutrition, chronic and acute infection, elevated energy expenditure, glucagon deficiency, malabsorption, abnormal intestinal transit time, and liver dysfunction. CFRD has been associated with increased malnutrition, increased pulmonary disease, and earlier death. Therefore, achievement of optimal nutritional status through adequate caloric intake and near-normalization of blood glucose levels are crucial in the nutritional management of CFRD.

Malabsorption can result in fat-soluble (A, D, E, K) vitamin deficiencies. Fernachak at Denver prospectively evaluated the biochemical status of vitamins A, D, and E in 127 infants diagnosed with CF through neonatal screening between January 1, 1984 and January 1, 1997 (7). Infants were treated with pancreatic enzymes and a daily

multiple vitamin. Vitamin levels were monitored at yearly evaluations. During the initial visit, a deficiency of 1 or more vitamins was present in 45.8% (44/96) of the patients. Approximately 64% had a single vitamin deficiency, and 36.4% had multiple vitamin deficiencies. Vitamin A and D deficiencies were typically corrected with supplementation during the follow-up period, but vitamin E deficiency persisted despite supplementation. Although a trend of higher fecal fat percentages was seen in those with a vitamin E deficiency than those with a normal status, the difference was not statistically significant. Alkaline phosphatase was the only liver function test to be significantly different between the vitamin E deficient and normal status group. The authors hypothesized that people with CF may require higher doses of vitamin E supplementation. However, compliance of taking the vitamin supplements to correct the deficiency may be a factor in deficiencies and fat-soluble vitamin deficiencies occurring frequently in CF patients despite supplementation. The authors concluded that this warrants routine monitoring of these serum vitamin levels as recommended by the CF Foundation Consensus guidelines.

Since pancreatic insufficiency effects absorption, it has been hypothesized the deficiency of the fat-soluble vitamins is related to the degree of pancreatic insufficiency. A study of 252 subjects consisting of 210 CF patients and 42 CF-free control patients compared serum levels of vitamin A and E (8). The CF patients were further subdivided into pancreatic sufficient and pancreatic insufficient groups. The CF population had significantly lower serum vitamin A and E levels (vitamin A $p<0.002$; vitamin E $p<0.001$) than the control group. A significant difference between the control and both groups of CF patients was seen for vitamin A levels (pancreatic sufficient $p<0.01$; pancreatic

insufficient $p<0.05$). The only significant difference seen in vitamin E status was between the control group and the pancreatic insufficient group($p<0.01$). The authors concluded that vitamin deficiency occurs despite pancreatic status.

Total energy needs are greatly increased for patients with CF, and it is not clear what proportion is due to maldigestion and what proportion is due to increased energy for breathing. Zemal and colleagues prospectively studied relationships among resting energy expenditure (REE), growth, nutritional status, and pulmonary function in subjects recruited from the CF Center at the Children's Hospital of Philadelphia (9). The best predictors of REE included fat-free mass and height. Pulmonary function did not strongly predict REE; however, percent ideal body weight predicted changes in pulmonary function over time. The authors indicated that REE might be an indicator of the severity of the CF independent of pulmonary function which confuses cause and effect.

The caloric needs of people with CF are approximately 120-150% of the RDA, yet most patients do not meet these energy requirements through daily dietary intake. Kawchak conducted a 3-year longitudinal, prospective study of dietary intake in prepubertal, pancreatic-insufficient children with CF (10). Twenty-five children with CF and 26 control children participated in the study. Energy and nutrient intakes calculated from 3-day weighed food records were compared with CF recommendations, recommended dietary allowance (RDA), and recommendations from the NHANES III. Despite the fact that the children with CF consumed more energy than the control children ($p=0.025$), they did not meet the CF recommended intakes of 120%RDA.

In another study on caloric needs of patients with CF, Horswill and colleagues

found an increase in energy expenditure with subjects fed supplemental drinks (11). Resting energy expenditure (REE) increased significantly in 8 subjects at The Hospital for Sick Children, Toronto, Canada who received nocturnal elemental feedings via a percutaneous endoscopic gastrostomy (PEG). No significant increase in protein turnover was seen with nocturnal feeding. Their percent of weight per height improved significantly from 74.5 ± 7.7 before PEG placement to 88.0 ± 7.0 ($p<0.005$) 1 year after PEG placement. Fat body mass and fat-free body mass also significantly increased. No significant changes occurred in pulmonary functions.

Since pulmonary and nutrition play an important role in optimizing the overall treatment of CF, the Cystic Fibrosis Foundation Consensus Committee has provided guidelines for nutritional assessment and intervention (10). The recommendations include monitoring growth and nutritional status at routine visits every 3 to 4 months. Weight, height, and head circumference until 2 years old are obtained and plotted on the growth chart. These measurements are then used to calculate ideal weight for height and to assess any significant changes. While many of the children may be at an appropriate weight for height, they may not be growing at an adequate height velocity. If a child's parents are at the 90 percentile for height and the child is only growing at the 25th percentile, he or she is not receiving adequate nutrition to reach his or her potential genetic height. The committee notes that particular attention needs to be paid to those children less than the 3rd percentile for height for possible stunting. Another part of the routine care includes assessment of dietary intake. A patient may complete a 3-day food record or a calorie count may be conducted when the patient is hospitalized which is often required annually.

This provides information to assess the adequacy of caloric, vitamin, and mineral intake. Malabsorption may impair growth and cause fat-soluble vitamin deficiencies. By analyzing the amount of fat in a patient's feces gathered over three days, the degree of malabsorption may be deteremined. Yearly complete blood count (CBC), serum albumin, and serum or plasma retinol and α-tocopherol levels are recommended to monitor for deficiencies and toxicities. The consensus committee has categorized nutritional management into four modalities: routine management, anticipatory guidance, supportive intervention, rehabilitative care, and resuscitative and palliative care. Routine nutritional management includes fat-soluble vitamin supplementation and pancreatic-enzyme replacement along with nutrition education and counseling. Patients with CF at risk for developing energy imbalance but are maintaining weight-height index $\geq$ 90% of ideal weight fall into the anticipatory guidance category. Goals in this category include education of increased energy needs, increase in caloric density of foods, increased monitoring of dietary intake, and behavioral assessment and counseling. Patients whose weight velocity decreases and/or weight-height index falls between 85 to 90% of ideal weight require supportive intervention. This includes oral supplements with commercial formulas such as Scandishakes, Pediasure, Carnation Instant Breakfast, and Boost. When weight-height index becomes consistently below 85% of ideal weight and noninvassive techniques have not been successful for 3 months, aggressive nutritional therapy should be initiated. Nasogastric tubes, gastrostomy tubes, and jejunostomy tubes have been successfully used methods for providing rehabilitative care. Progressive nutritional failure and weight-height index <75% of ideal weight indicate need for resuscitative and palliative

care which includes all of the other interventions and total parental nutrition.

Additional studies of PEG placement are warranted due to the potential benefit of improved nutritional status and the associated decreased complications of CF. The purpose of this research is 2-fold:

1) To determine the optimal time to place a percutaneous endoscopic gastrostomy to achieve optimal nutritional status, lung function, and genetic growth potential.

2) To measure the barriers toward PEG tube placement for patients, parents, and health professionals.

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CHAPTER II

PERCUTANEOUS ENDOSCOPIC GASTROSTOMY (PEG) PLACEMENT TIME

Abstract

A retrospective chart review was conducted on pediatric patients at the Intermountain Cystic Fibrosis Center who had a percutaneous endoscopic gastrostomy (PEG) placed between 1993 and 1999. Height velocity improved significantly in the group of patients with a PEG placed; however, pulmonary function declined more significantly over time.

Introduction

Nutrition plays an integral role in survival of people with CF and has a strong positive relationship with pulmonary status; therefore, intervention should be initiated early in the course of the disease (1). Pulmonary status is measured by spirometry tests which include, forced expiratory volume in 1 second after a full breath (FEV_1) and forced vital capacity (FVC). Based on height, age, and gender, an expected value is generated. Results are reported as percent of predicted FEV_1 and FVC. A direct association between FEV_1, clinical status, and survival exists. Long-term nutritional supplementation via a gastrostomy has been found to improve pulmonary and nutritional status; however, further research is needed to determine the optimal time to initiate these supplemental feedings and the attitudes toward initiation (1).

Levine (2) conducted a review of the literature to determine which CF patients are

candidates for aggressive nutrition therapy. He first summarized some of the common findings; 50% of CF patients are lower than the 10th percentile in height for age or weight for age, and they have increased resting energy expenditure (REE) regardless of pulmonary status. He concluded that since malnutrition is an important contributor to morbidity and mortality in patients with CF, aggressive nutrition therapy should be considered in any patient with CF at the first sign of deterioration in nutritional status and, possibly, in pulmonary function. It was also recommended that more studies to determine which patients are suitable candidates for nutritional therapy and when to initiate nutritional supplementation be conducted, and that more effort must be made to understand the increased REE in CF patients.

In a study to determine any potential benefits of supplemental feedings on pulmonary function and growth in patients with CF, 10 undernourished children aged 3 to 13.2 years were observed before and 1 to 2 years after enteral nutrition supplementation (3). Seven of the patients received the nocturnal feedings through a gastrostomy tube. Data on nutritional, clinical, and pulmonary status were collected at intervals one year prior to the supplementation and 1 year during the supplementation. Changes in pulmonary functions were compared with 14 other CF patients matched for sex, height, and forced expiratory volume in 1 second (FEV_1). The study group experienced significantly greater gains in weight and height than the control group. Pulmonary decline decreased significantly in the study group along with the number of pulmonary exacerbations per year.

In a 5-year follow-up study to determine the effect of aggressive nutrition support

on growth and pulmonary function in the short and long term, undernourished children with CF were matched according to height, pulmonary function, and sex (4). One group received supplements for a median of 1.35 years. The supplemental group had lower mortality and significantly higher height and weight *z* scores at 4 and 5 years. The slope for declining pulmonary function was significantly smaller at 3 years for the supplemented group, and no difference was seen after 5 years. Since the improvement continued after supplementation was discontinued, the authors suggested that supplementation for periods longer than 1 year may produce greater gains and prolong the improvement in pulmonary function.

Long-term placement of gastrostomy tube feedings have also been studied to determine if there are benefits in lung function with supplemental nutrition. Walker and Gozal (1) followed the pulmonary function of CF patients for 2 years after the placement of a percutaneous endoscopic (PEG) tube. The criteria for a PEG tube placement was the patient's weight lower than 85% ideal weight for height, weight loss for more than 2 months, and plateau in weight gain for 6 months. After PEG placement, nutritional and pulmonary status were followed for 2 years. The authors concluded that long-term nutritional benefit of PEG placement is critically dependent on presurgical pulmonary function. They suggested that PEG placement be considered an early intervention rather than one of last resort.

An additional study of the effect of nocturnal tube feedings on pulmonary function was conducted at Children's Hospital in Hannover Germany by Steinkamp and Horst von der Hardt (5). They reported that nocturnal PEG feedings of malnourished patients with

CF improved nutritional and pulmonary status. Fourteen patients who received supplemental nocturnal feedings via a PEG were followed 26 months. The weight for height was 77.8% at time of initiation and improved by 9% one year after placement. Lung functions improved significantly between initial placement and one year.

It has been concluded that PEGs improve growth and nutrition status in patients with CF. Earlier placement of PEG, before declining to 85% ideal body weight, may have additional benefits. The purpose of this study was to determine the optimal time to place a percutaneous endoscopic gastrostomy to achieve optimal nutritional status, lung function, and genetic growth potential.

Methods

Population

The Intermountain Cystic Fibrosis Center consisted of the adult center at the University of Utah Hospital and the pediatric center at Primary Children's Medical Center in Salt Lake City, Utah. Approximately 250 patients were seen at this center, and of this population, 22 pediatric patients and 10 adult patients had a gastrostomy placed between 1993 and 1999. The 22 pediatric patients and a matched-control were selected for the study.

Study design

Medical charts at the Intermountain Cystic Fibrosis Center were retrospectively reviewed for pulmonary and anthropometric parameters of the CF patients. Data was

collected on the pulmonary and anthropometric indices that led to gastrostomy placement in the patients with a PEG and the effects on pulmonary function and growth 12 months after PEG placement. These patients were then matched with patients without a PEG based on pulmonary status, age, and gender at time of PEG placement. Height, weight, FEV_1, and FVC, of the PEG and non-PEG patients were obtained and analyzed for differences.

Data Management and Statistical Analysis

Results of pulmonary function tests were collected for 1 month prior to placement, 1 month after PEG placement, and 3 non-sick measurements within 24 months after PEG placement. Independent t-tests were used to measure differences in weight, height, and pulmonary functions over time. A paired t-test was conducted between the non-PEG controls matched with the patients with PEGs to determine if PEG placement improves nutritional and pulmonary status.

Results

Short-term pulmonary function tests, those measurements taken 1 month after PEG placement, declined significantly. FVC% predicted fell from 68 ± 19 to 59 ± 16 ($p=0.014$), and FEV_1 fell from 56 ± 21 to 49 ± 15 ($p=0.02$). Long-term data, average of 3 non-sick measurements within 24 months of PEG placement excluding short-term data, showed a significant decrease in pulmonary function. The mean % predicted FVC and FEV_1 were 8.6% ($p=0.034$) and 8.2% ($p=0.02$) lower following PEG placement. The

PEG group had improved height velocity compared to the non-PEG group ($p=0.048$). However, the PEG group had significantly greater declines in pulmonary function over time.

Discussion

PEG placement was shown to improve nutritional status; however, it is somewhat controversial as to whether or not it improves pulmonary function. The CF Consensus Committee recommends initiation of gastrostomy placement based on percent ideal weight for height being less than 85% or a plateau in weight gain for 3 months (6). Yet, PEGs were placed in patients greater than 85% of ideal weight for height. Due to the small number of gastrostomies placed in people with CF, it is difficult to statistically verify the benefits of earlier placement. Patients with decreased pulmonary status do not do as well with PEG placement secondary to the need to be able to withstand an initial decline in pulmonary functions immediately following PEG placement. Further multi-center studies need to be conducted to determine the nutritional and pulmonary effects of earlier placement.

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CHAPTER III

QUESTIONNAIRE REGARDING ATTITUDES OF PEOPLE WITH CYSTIC FIBROSIS TOWARD PERCUTANEOUS ENDOSCOPIC GASTROSTOMY PLACEMENT

Abstract

A PEG and non-PEG questionnaire was developed to identify concerns toward PEG placement. Questionnaires were mailed to patients seen in accredited cystic fibrosis centers in Arizona, Colorado, Idaho, Montana, Nevada, and Utah. For patients 10 to 18 years old, separate questionnaires linked by identification number were sent to the parent and child. The response rate for the PEG questionnaire was 54.25% and for the non-PEG questionnaire was 24%. Ninety-six percent of the patients with a PEG reported that weight was a problem at time of PEG placement, and 91% reported weight gain after PEG placement. Sixty-four percent of patients with a PEG would have a PEG placed if they had to make the decision of whether or not to place it again. Sixty-one percent of patients thought a PEG would look bad, and 59.4% would be embarrassed to have a PEG. A lack of knowledge of PEG tubes was expressed by 49.3% of the patients, and 35.4% had no opinion regarding their knowledge of PEG tubes. A lack of knowledge regarding PEG tubes exists amongst the CF population.

Introduction

Nutrition plays a vital role in the complex treatment regimen of cystic fibrosis

(CF). Inadequate weight gain and malnutrition in people with CF have been shown to be highly correlated with pulmonary decline, osteoporosis, and delayed puberty. Due to the nutritional complications of CF, extra emphasis is placed on nutrition. Therefore, many patients with CF have challenges with eating patterns and behaviors. Mealtime frequently becomes a battleground between children expressing autonomy and parents trying to provide adequate nutrition. Stark and colleagues found that children with CF when compared to children without CF talked more, spent more time away from the table, refused more food, and were more noncompliant in response to commands to eat. Regardless of whether or not a child had CF, if he or she spent longer than 20 minutes at dinner, he or she consumed a lower percent of the RDA (92% vs 97%) and fell into a lower weight percentile compared to children who spent less than 20 minutes at dinner (1). The symptoms of CF may include foul-smelling, oily stool and abdominal distress secondary to malabsorption and maldigestion of nutrients. In order to diminish or eliminate these symptoms, many children with CF refuse to eat. The aforementioned complications of eating increase the frustration of people with CF trying to consume 120-150% of the RDA. To alleviate the eating battle, or simply to increase the caloric intake of people with CF, gastrostomy placement has been recommended.

The decision to use a percutaneous endoscopic gastrostomy (PEG) for long-term nutritional support involves several variables. The level of family involvement and commitment influences the success of PEG placement as a means of nutritional support and factors into the decision-making process. Physicians' opinions on PEG placement also influence the decision. Van Rosendaal and colleagues (2) studied the decision making

process in determining whether or not to place a PEG. They found that physicians and family members input had the greatest impact on the process. According to an Australian study of adolescents with CF, family members provided more tangible support. This included reminders to perform treatment tasks, helping out with treatment tasks, or actually doing treatment tasks (3). This same study also looked at the support friends gave to the adolescents with CF. It showed that friends provided more emotional support, which related to acceptance of CF; however, 20% of these adolescents expressed concerns about disclosing to their friends that they had CF (3).

The daily treatment regimen for people with CF involves of myriad of tasks which include chest physiotherapy, use of inhalant medications, high-calorie diets, pancreatic enzymes, and vitamin supplements. All of these tasks prove to be time-consuming and stressful on the parent-child relationship; yet, compliance significantly influences life expectancy. Eddy and colleagues (4) looked at marital adjustment, family characteristics, and parent-child stress in relationship to compliance. Parents with lower stress reported better compliance with dietary and nutritional therapies. These multiple psychosocial factors support the CF Foundation Consensus Committee's recommendation of family assessment and education regarding enteral nutrition prior to initiation (5).

Eating not only serves the purpose of providing calories and nutrients for an individual, but it also involves manifold psychological factors. Therefore, the decision to use long-term gastrostomy feedings takes on multiple meanings. Some may view placement as giving up hope and a sign that the disease is getting worse. If the family has experienced continuous battles over food and lengthy mealtimes as seen in patients with

CF, gastrostomy placement may be seen as a welcome relief. Some patients and parents may view gastrostomy placement as failure to take good care of the person. Whatever the meaning may be for each person deciding whether or not to place a gastrostomy, the person's individual needs deserve respect (6).

Long-term gastrostomy feedings appear to be a safe and effective means of improving nutrition status of malnourished CF patients as determined in a longitudinal, retrospective study conducted by Rosenfeld and colleagues (7). In this study weight percentile for age and weight as a percentage of ideal body weight improved significantly 6 to 18 months after placement of the gastrostomy (an increase from the 2nd percentile weight to the 12th percentile weight or, 88% ideal body weight to 90% ideal body weight). Height percentile increased significantly 18 to 30 months after placement of gastrostomy from the 6th percentile for height to the 10th percentile for height. Weight continued to improve to 93% ideal body weight 18 to 30 months after placement.

According to the 1998 Cystic Fibrosis Foundation Patient Registry for Centers in Utah, Arizona, Colorado, and New Mexico, 8.73% of the patients had a gastrostomy at that time (8). It was also reported that 14.16% of the children and 21.20% of the adults fell below 85% of ideal body weight (IBW). The CFF Consensus Committee recommended aggressive nutritional therapy such as percutaneous endoscopic gastrostomy (PEG) when IBW falls below 85% indicating 5.43% to 12.77% of patients with CF were not receiving the recommended treatment (5, 8). Despite the known benefits of PEG placement, patients refuse this nutritional therapy. The purpose of this study was to better understand patient and family attitudes toward PEG placement.

Methods

Population

The population for this study was selected from the following accredited cystic fibrosis centers: The Children's Hospital (pediatric) and University of Colorado Health Sciences Center (adult), Denver, Colorado and its affiliate in Billings, Montana; Tucson Cystic Fibrosis Center, University of Arizona Health Sciences Center, Tucson, Arizona; and Intermountain Cystic Fibrosis Center which included Primary Children's Medical Center (pediatric) and University of Utah School of Medicine (adult) in Salt Lake City, Utah; Pocatello Children and Adolescent Clinic, Pocatello, Idaho; and Cystic Fibrosis Affiliate Program, Meridian, Idaho. These CF centers enrolled patients from the states of Arizona, Colorado, Idaho, Montana, Nebraska, Nevada, Utah, and Wyoming representing people from urban and rural areas. Patients aged 10 years and older and parents of children aged 0 to 18 years old who attended these accredited CF centers were invited to participate in the study. This age was decided upon based on the reading level of the questionnaire as dictated by Primary Children's Medical Center's IRB.

Questionnaires

Researchers at the Intermountain CF Center developed a pilot questionnaire for patients with a PEG that identified concerns patients and families had toward PEG placement. This information was used to develop 4 corresponding questionnaires for: 1) patients aged 10 years and older with a PEG (Appendix G); 2) parents of children aged 0 to 18 years with a PEG (Appendix H); 3) patients aged 10 years and older without a PEG

(Appendix E); 4) parents of children aged 0 to 18 years without a PEG (Appendix F). The questionnaires for the children and parents differed only in first and second person format. Content validity was established by physicians, nurses, social workers, and dietitians who worked with the CF population.

The questionnaires included a self-reported age, weight, height, number of days hospitalized within the last year, health in last year, and activity level in past year. The next section consisted of statements regarding PEG placement each followed by a 5-category Likert scale (1=strongly agree, 2=agree, 3=no opinion, 4=disagree, 5=strongly disagree).

A follow-up questionnaire similar to the questionnaires for patients with CF was sent to professionals working with the CF population in Tucson, Arizona; Denver, Colorado; Albuquerque, New Mexico; and Salt Lake City, Utah, to determine their attitudes toward PEG placement (Appendices I, J).

Data Management and Collection

The institutional review boards from Utah State University; The Children's Hospital, University of Colorado Health Sciences Center, Denver, Colorado; University of Arizona, Tucson, Arizona; and University of Utah and Primary Children's Medical Center, Salt Lake City, Utah; approved the study. A cover letter described the purpose of the study, invited the patients and/or parents to participate, and assured confidentiality (Appendices A, B, C). The packet for the non-PEG questionnaires included an explanation and illustration of a gastrostomy (Appendix D). Non-PEG and PEG

questionnaire packets were mailed to all patients and/or their parents attending the aforementioned CF centers, except Tucson, Arizona. Participants from Tucson, Arizona completed the non-PEG questionnaire during a routine clinic visit, and the PEG questionnaires were mailed to all patients and/or parents. For patients between the ages of 10 to 18 years, the parents and children were sent separate questionnaires linked by an identification number for comparison of parent and children's attitudes toward PEG placement. A reminder PEG-questionnaire was sent to potential participants 3 months after the original one was distributed. Participants anonymously completed and returned the questionnaire to Primary Children's Medical Center in a prepaid self-addressed envelope.

Data Management and Statistical Analysis

All data were collected and entered into SPSS™ for statistical analysis. Descriptive statistics were used to report age, gender, days hospitalized in past year, overall health and activity in the past year, and responses to the statements regarding PEG placement. Pearson correlation coefficients were conducted to determine relationships between responses. Alpha reliability analysis measured internal consistency of the questionnaire. Paired t-tests were used to determine if parent's and children's responses differed from each other. An independent t-test was used to identify differences between attitudes toward PEG placement of people without a PEG and people with a PEG.

Results

PEG Questionnaire

Questionnaires were returned from the states of Utah, Arizona, Colorado, Montana, and Idaho. The overall response rate for the PEG questionnaire was 54.25% (51/94). Thirty-six individual patients were identified amongst the 51 completed questionnaires. Of the 36 individuals, 15 of them had dual representation secondary to parent and child completing separate questionnaires for the same individual.

Seventy-two percent (26/36) of the individual patients were female, and the mean age was $12^{7}/_{12}$ years ranging between the ages of $2^{10}/_{12}$ years to 26 years old. Patients were reported to have been hospitalized an average of 15.12 days in the past year ranging from 0 days to 70 days. The median response for perceived health in the past year was reported as good, and the median response for activity level compared to peers was reported to be about the same as peers. Table 1 shows the mean and median response to the statements found in the PEG questionnaires.

Ninety-three percent of the parents and 96% of the patients reported that weight was a problem at the time of PEG placement. After PEG placement, 91% of the patients reported weight gain; 73% said the PEG had helped them grow; 59% reported to have more energy; and 77% reported they were healthier after PEG placement. When asked whether or not they would have a PEG placed if they made the decision again, 79% of the parents and 64% of the patients said they would have the PEG placed. Tables 2 and 3 show the frequency of responses to the statements on the questionnaire.

The results of Pearson correlations between variables on the questionnaire are

reported in Table 4. If a respondent felt the PEG interfered with sports and other activities, he or she most likely felt that a PEG looked bad and was embarrassing. Weight gain was usually reported with a report of the PEG helping the patient grow. Those respondents who thought the PEG looked bad, was embarrassing, and hurt were more likely not have a PEG placed if they had to decide whether or not to place it again.

According to a paired t-test, children ages 10 to 18 years responded significantly different from their parents in the rating of overall health in the past year ($p=0.04$); status of lungs before PEG placement ($p=0.04$); and if the PEG looked bad ($p=0.02$). Children reported their health better than their parents, and they also said their lungs were not as healthy prior to PEG placement. In response to the statement that a PEG looks bad, the children had no opinion while the parents disagreed that the PEG looked bad. No other significant differences were found between parents and children.

Non-PEG Questionnaire

Questionnaires were returned from the states of Arizona, Colorado, Idaho, Montana, Nebraska, Nevada, Utah, and Wyoming. The response rate for the non- PEG was 24% (248/1030). This does not include ten questionnaires that were completed in clinic and returned from Arizona. Two-hundred three patients were identified amongst the 248 completed questionnaires. Of the 203 individuals, 45 of them had dual representation secondary to parent and child completing separate questionnaires for the same individual. Fifty-one percent (104/203) of the patients without a PEG were male, and 49% (99/203) were female. The mean age for the non-PEG patients was 16 years with a range of 0.5

Table 1 Mean and Standard Deviation/Median Response to PEG Questionnaires

Statement	Mean/Median Response All patients*	Mean/Median Response Parents**	Mean/Median Response Patients***
When my PEG was placed, I had healthy lungs.	2.85±1.22 2.00 n=35	2.69±1.26 2.00 n=29	2.81±1.21 2.00 n=21
My weight was a problem when the PEG was placed	1.47±0.74 1.00 n=36	1.41±0.73 1.00 n=29	1.36±0.58 1.00 n=22
I ate enough before my PEG was placed.	3.75±1.38 4.00 n=36	4.00±1.31 4.00 n=29	3.45±1.50 4.00 n=22
I have gained weight with my PEG.	1.58±0.84 1.00 n=36	1.55±0.87 1.00 n=29	1.55±0.80 1.00 n=22
I thought that getting a PEG meant my CF was getting worse.	3.44±1.23 3.50 n=36	3.41±1.21 4.00 n=29	3.22±1.31 3.00 n=22
My PEG makes it hard to do sports or other activities.	3.36±1.29 4.00 n=36	3.21±1.29 4.00 n=29	3.36±1.40 4.00 n=22
I think my PEG looks bad.	3.33±1.33 4.00 n=36	3.90±0.90 4.00 n=29	2.86±1.42 3.00 n=22
I would be embarrassed if my friends knew I had a PEG.	3.58±1.23 4.00 n=36	3.48±1.18 4.00 n=29	3.45±1.37 4.00 n=22
My PEG hurts.	3.83±1.11 4.00 n=36	3.79±1.01 4.00 n=29	3.68±1.32 4.00 n=22
My family has trouble buying the formula.	3.31±1.55 4.00 n=36	3.07±1.56 4.00 n=29	3.45±1.63 4.00 n=22
The PEG has helped me grow taller, gain weight, and/or develop puberty.	1.92±0.94 2.00 n=36	1.66±0.94 1.00 n=29	2.05±0.95 2.00 n=22
The PEG has helped my lungs.	2.86±0.88 3.00 n=36	2.55±0.95 3.00 n=29	3.05±0.86 3.00 n=21
I have more energy with my PEG.	2.50±1.16 2.00 n=36	2.34±1.20 2.00 n=29	2.55±1.10 2.00 n=22
I am healthier now after the PEG.	1.89±1.01 2.00 n=36	1.76±0.79 2.00 n=29	1.95±1.09 2.00 n=22
If I could do it over again, I would NOT have a PEG.	3.89±1.35 4.00 n=36	4.10±1.29 5.00 n=29	3.64±1.47 4.00 n=22

Response Key: 1=strongly agree, 2=agree, 3=no opinion, 4=disagree, 5=strongly disagree

* N includes all patients and parents where a child did not respond.

** N includes all parents of patients 0 to 18 years of age

*** N includes all patients 10 years and older

Table 2 Frequencies of Parents' Responses to PEG Questionnaire

Statement	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
When my child's PEG tube was placed, he or she had healthy lungs. (n=29)	13.8%	44.8%	10.3%	20.7%	10.3%
My child's weight was a problem when the PEG was placed. (n=29)	69%	24.1%	3.4%	3.4%	0%
My child ate enough before his or her PEG was placed. (n=29)	6.9%	13.8%	0%	31%	48.3%
My child has gained weight with his or her PEG. (n=29)	62.1%	27.6%	3.4%	6.9%	0%
I thought that getting a PEG meant my child's CF was getting worse. (n=29)	6.9%	20.7%	13.8%	41.4%	17.2%
My child's PEG makes it hard for him or her to do sports or other activities. (n=29)	10.3%	27.6%	6.9%	41.4%	13.8%
My child's PEG looks bad. (n=29)	0%	13.8%	3.4%	62.1%	20.7%
My child would be embarrassed if his or her friends knew he or she had a PEG. (n=29)	6.9%	17.2%	13.8%	44.8%	17.2%
My child's PEG is painful. (n=29)	3.4%	10.3%	10.3%	55.2%	20.7%
We have difficulty affording the formula. (n=29)	27.6%	10.3%	10.3%	31%	20.7%
The PEG has helped my child grow taller, gain weight, and/or develop puberty. (n=29)	58.6%	24.1%	10.3%	6.9%	0%
The PEG has helped my child's lungs. (n=29)	17.2%	24.1%	44.8%	13.8%	0%
My child has more energy with his or her PEG. (n=29)	31%	27.6%	20.7%	17.2%	3.4%
My child is healthier now after the PEG. (n=29)	41.4%	44.8%	10.3%	3.4%	0%
If I could do it over again, my child would NOT have a PEG. (n=29)	6.9%	10.3%	3.4%	24.1%	55.2%

Table 3 Frequencies of Patients' Responses to PEG Questionnaire

Statement	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
When my PEG tube was placed, I had healthy lungs. (n=21)	9.50%	42.90%	14.30%	23.80%	9.50%
My weight was a problem when the PEG was placed. (n=22)	68.20%	27.30%	4.50%	0.00%	0.00%
I ate enough before my PEG was placed. (n=22)	13.60%	22.70%	0.00%	31.80%	31.80%
I have gained weight with my PEG. (n=22)	63.60%	27.30%	4.50%	4.50%	0.00%
I thought that getting a PEG meant my CF was getting worse. (n=22)	9.10%	22.70%	27.30%	18.20%	22.70%
My PEG makes it hard to do sports or other activities. (n=22)	9.10%	27.30%	4.50%	36.40%	22.70%
I think my PEG looks bad. (n=22)	22.70%	22.70%	13.60%	27.30%	13.60%
I would be embarrassed if my friends knew I had a PEG. (n=22)	13.60%	13.60%	9.10%	40.90%	22.70%
My PEG hurts. (n=22)	9.10%	13.60%	9.10%	36.40%	31.80%
My family has trouble buying the formula. (n=22)	22.70%	9.10%	4.50%	27.30%	36.40%
The PEG has helped me grow taller, gain weight, and/or develop puberty. (n=22)	31.80%	40.90%	18.20%	9.10%	0.00%
The PEG has helped my lungs. (n=21)	0.00%	28.60%	42.90%	23.80%	4.80%
I have more energy with my PEG. (n=22)	13.60%	45.50%	18.20%	18.20%	4.50%
I am healthier now after the PEG. (n=22)	40.90%	36.40%	13.60%	4.50%	4.50%
If I could do it over again, I would NOT have a PEG. (n=22)	18.20%	0.00%	18.20%	27.20%	36.40%

Table 4 PEG Questionnaire Pearson Correlations

Variables	All Patients	Parents Only	Patients Only
age x days hospitalized	0.518** (n=33)	0.465*(n=26)	0.403 (n=20)
age x health	-0.516** (n=34)	-0.310 (n=28)	-0.549** (n=21)
age x activity	-0.656** (n=33)	-0.482**(n=28)	-0.638**(n=20)
age x looks	-0.424* (n=35)	-0.277 (n=28)	-0.099 (n=22)
age x embarrass	0.195 (n=35)	0.010 (n=28)	0.429* (n=22)
age x pay	0.460** (n=35)	0.381* (n=28)	0.419 (n=22)
age x healthier	0.371* (n=35)	-0.051 (n=28)	0.553** (n=22)
gender x activity	-0.461** (n=34)	-0.298 (n=29)	-0.588**(n=20)
gender x sports	0.322 (n=36)	0.285 (n=29)	0.473*(n=22)
days hospitalized x health	-0.527** (n=34)	-0.511** (n=27)	-0.547* (n=20)
days hospitalized x activity	-0.473**(n=33)	-0.413* (n=27)	-0.495* (n=19)
days hospitalized x healthy lungs	0.197 (n=33)	0.420*(n=27)	0.189 (n=19)
days hospitalized x looks	-0.572** (n=34)	-0.237 (n=27)	-0.457* (n=20)
days hospitalized x healthier	0.383* (n=34)	-0.025 (n=27)	0.464* (n=20)
health x activity	0.691** (n=34)	0.649** (n=29)	0.701** (n=20)
health x healthy lungs	-0.379* (n=34)	-0.159 (n=29)	-0.708** (n=20)
health x looks	0.408* (n=35)	0.272 (n=29)	0.354 (n=21)
activity x healthy lungs	-0.184 (n=33)	-0.081 (n=29)	-0.537* (n=19)
activity x weight problem	0.392* (n=34)	0.466* (n=29)	0.108 (n=20)
activity x pay	-0.295 (n=34)	-0.046 (n=29)	-0.448* (n=20)
activity x healthier	-0.330 (n=34)	0.025 (n=29)	-0.452* (n=20)
healthy lungs x gained	-0.371* (n=35)	-0.263 (n=29)	-0.503* (n=21)
healthy lungs x hurts	0.433** (n=35)	0.509** (n=29)	0.540* (n=21)
healthy lungs x grow	-0.369* (n=35)	-0.276 (n=29)	-0.334 (n=21)
healthy lungs x healthier	-0.369* (n=35)	-0.440* (n=29)	-0.227 (n=21)
healthy lungs x not again	0.380* (n=35)	0.461* (n=29)	0.430 (n=21)
weight problem x ate enough	-0.414* (n=36)	-0.372* (n=29)	-0.416 (n=22)
ate enough x not again	0.353* (n=36)	0.465* (n=29)	0.273 (n=22)
gained x hurts	-0.291 (n=36)	-0.474** (n=29)	-0.381 (n=22)
gained x grow	0.571** (n=36)	0.681** (n=29)	0.594** (n=22)
gained x energy	0.308 (n=36)	0.426* (n=29)	0.270 (n=22)
gained x healthier	0.382* (n=36)	0.620** (n=29)	0.300 (n=22)
gained x not again	-0.319 (n=36)	-0.562** (n=29)	-0.284 (n=22)
sports x looks	0.510** (n=36)	0.357 (n=29)	0.762** (n=22)
sports x embarrass	0.458** (n=36)	0.493** (n=29)	0.391 (n=22)
sports x pay	0.430**(n=36)	0.277 (n=29)	0.566** (n=22)
sports x not again	0.369* (n=36)	0.393* (n=29)	0.427* (n=22)
looks x embarrass	0.420* (n=36)	0.384* (n=29)	0.521* (n=22)
looks x pay	0.227 (n=36)	0.133 (n=29)	0.522* (n=22)
looks x not again	0.483** (n=36)	0.317 (n=29)	0.591** (n=22)
embarrass x hurts	0.199 (n=36)	0.443* (n=29)	0.110 (n=22)
embarrass x pay	0.340* (n=36)	0.349 (n=29)	0.416 (n=22)
embarrass x not again	0.507** (n=36)	0.597** (n=29)	0.466* (n=22)
hurts x pay	0.231 (n=36)	0.485** (n=29)	0.203 (n=22)
hurts x energy	-0.334* (n=36)	-0.262 (n=29)	-0.398 (n=22)
hurts x healthier	-0.375* (n=36)	-0.423* (n=29)	-0.407 (n=22)
hurts x not again	0.542** (n=36)	0.645** (n=29)	0.527* (n=22)
pay x not again	0.250 (n=36)	0.387* (n=29)	0.433* (n=22)
grow x helped lungs	0.204 (n=36)	0.504** (n=29)	-0.006 (n=21)
grow x energy	0.276 (n=36)	0.490** (n=29)	0.203 (n=22)
grow x healthier	0.625** (n=36)	0.659** (n=29)	0.646** (n=22)
grow x not again	-0.415*(n=36)	-0.560** (n=29)	-0.398 (n=22)
energy x healthier	0.563** (n=36)	0.620** (n=29)	0.537** (n=22)
helped lungs x energy	0.459** (n=35)	0.547* (n=29)	0.452* (n=21)
helped lungs x healthier	0.317 (n=35)	0.377* (n=29)	0.317 (n=21)
healthier x not again	-0.430* (n=36)	-0.608** (n=29)	-0.339 (n=22)

* Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

year to 52 years of age. Self-reported days hospitalized ranged from 0 to 105 days with a mean of 7.28±15.36 days. Seventy-seven percent of the patients' overall health in the past year was reported as either good or very good with 51% reporting activity level equal to peers. Only 10% of the people without a PEG reported that a member of the CF health care team had recommended PEG placement. Table 5 reports the mean and median responses for the non-PEG questionnaire.

Of those patients without a PEG, 55% either disagreed or strongly disagreed that their weight was a problem; 64% either disagreed or strongly disagreed that they did not want to gain weight; and 68% thought they ate enough. Fifty-three percent thought a PEG would look bad, and 55% would be embarrassed to have a PEG. Getting a PEG meant the CF was getting worse to 55.4% of the patients. A lack of knowledge concerning PEG tubes was expressed for 61% of the patients with 20.3% having no opinion as to whether or not they knew enough about the pros and cons of PEG placement. Tables 6 and 7 report the frequency of responses to the statements on the non-PEG questionnaire.

According to a paired t-test, children ages 10 to 18 years and their parents responded highly significantly different to whether a PEG would limit participation in sports and other activities ($p=0.000$); significantly different to if a PEG would be painful ($p=0.02$); if a child would have a PEG placed if he or she was losing weight ($p=0.012$); and a nasogastric (NG) tube would be preferred if nutrition support was indicated ($p=0.044$). The children felt it would be harder to participate in sports or other activities with a PEG than their parents. They also thought a PEG would be more painful. If their

Table 5 Non-PEG Questionnaire Mean and Standard Deviation/ Median Responses

Statement	Mean/Median Response All patients	Mean/Median Response Parents	Mean/Median Response Patients
My weight is a problem.	3.30±1.29 4.00 n=202	3.41±1.32 4.00 n=125	3.34±1.26 4.00 n=120
I don't want to gain weight.	3.65±1.21 4.00 n=202	3.83±1.04 4.00 n=125	3.40±1.44 4.00 n=121
My family or friends think I don't eat enough.	3.67±1.16 4.00 n=202	3.66±1.17 4.00 n=125	3.63±1.11 4.00 n=121
CF patients with lung problems need a PEG.	3.43±0.83 3.00 n=200	3.41±0.87 3.00 n=123	3.48±0.81 3.00 n=121
CF patients with no lung problems do not need a PEG.	3.14±0.80 3.00 n=201	3.14±0.81 3.00 n=125	3.01±0.84 3.00 n=119
It would be hard to do sports or other activities with a PEG.	2.73±0.96 3.00 n=201	2.92±0.94 3.00 n=125	2.38±0.97 2.00 n=119
A PEG looks bad.	2.53±0.97 2.00 n=202	2.70±0.95 3.00 n=125	2.30±0.93 2.00 n=121
A PEG would embarrass me.	2.44±1.06 2.00 n=202	2.48±1.02 2.00 n=125	2.32±1.07 2.00 n=121
A PEG would hurt.	2.76±0.88 3.00 n=201	2.80±0.88 3.00 n=124	2.62±0.97 3.00 n=121
Getting a PEG means my CF is getting worse.	2.58±1.05 2.00 n=202	2.68±1.06 3.00 n=125	2.55±1.04 2.00 n=121
My insurance/HMO/Medicaid would pay for the formula used in PEG feedings.	2.89±0.86 3.00 n=200	2.98±0.84 3.00 n=123	2.78±0.87 3.00 n=120
A PEG would help me grow taller, gain weight, or develop puberty.	2.75±0.87 3.00 n=201	2.76±0.89 3.00 n=125	2.74±0.80 3.00 n=120
A PEG may help my lungs.	3.04±0.89 3.00 n=201	3.09±0.90 3.00 n=125	3.06±0.93 3.00 n=120
A PEG may give me more energy.	2.68±0.87 3.00 n=200	2.74±0.87 3.00 n=124	2.63±0.88 3.00 n=120
If I was losing weight, I would want a PEG.	2.92±1.04 3.00 n=201	2.68±0.94 3.00 n=125	3.21±1.14 3.00 n=120
I know enough about the good and bad things about PEG tubes.	3.61±1.13 4.00 n=202	3.63±1.17 4.00 n=125	3.46±1.01 3.00 n=121
If my appetite got worse, I would want a PEG .	3.03±0.99 3.00 n=201	2.88±0.92 3.00 n=124	3.24±1.03 3.00 n=121
If I needed extra nutrition, I would prefer a nasogastric (NG) tube.	3.41±1.12 3.00 n=201	3.51±1.05 3.00 n=125	3.42±1.19 3.00 n=120

Response Key: 1=strongly agree, 2=agree, 3=no opinion, 4=disagree, 5=strongly disagree

* N includes all patients and parents where a child did not respond.

** N includes all parents of patients 0 to 18 years of age

*** N includes all patients 10 years and older

Table 6 Frequencies of Patients' Responses to Non-PEG Questionnaire

Statement	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
My weight is a problem. (n=129)	7.00%	27.10%	13.20%	32.60%	20.20%
I don't want to gain weight. (n=130)	13.10%	20.80%	7.70%	27.70%	30.80%
My family or friends think I don't eat enough. (n=130)	0.80%	22.30%	14.60%	36.90%	25.40%
CF patients with lung problems need a PEG.(n=130)	1.50%	4.60%	48.50%	35.40%	10.00%
CF patients with no lung problems do not need a PEG. (n=127)	4.70%	15.70%	54.30%	22.00%	3.10%
It would be hard to do sports or other activities with a PEG.(n=128)	15.60%	43.00%	26.60%	11.70%	3.10%
A PEG looks bad.(n=130)	19.20%	41.50%	28.50%	10.80%	0.00%
A PEG would embarrass me.(n=130)	23.80%	35.40%	26.20%	12.30%	2.30%
A PEG would hurt.(n=130)	14.60%	24.60%	44.60%	13.80%	2.30%
Getting a PEG means my CF is getting worse. (n=130)	12.30%	43.80%	19.20%	22.30%	2.30%
My insurance/HMO/Medicaid would pay for the formula used in PEG feedings. (n=128)	7.00%	26.60%	53.10%	7.80%	5.50%
A PEG would help me grow taller, gain weight, or develop puberty. (n=129)	3.90%	34.90%	48.80%	9.30%	3.10%
A PEG may help my lungs. (n=129)	1.60%	31.00%	41.10%	18.60%	7.80%
A PEG may give me more energy. (n=129)	6.20%	45.00%	34.10%	12.40%	2.30%
If I was losing weight, I would want a PEG. (n=129)	6.20%	22.50%	28.70%	27.90%	14.70%
If my appetite got worse, I would want a PEG . (n=130)	3.80%	23.80%	29.20%	32.30%	10.80%
I know enough about the good and bad things about PEG tubes. (n=130)	3.80%	11.50%	35.40%	33.10%	16.20%
If I needed extra nutrition, I would prefer a nasogastric (NG) tube. (n=129)	7.80%	11.60%	38.00%	20.20%	22.50%

Table 7 Frequencies of Parents' Responses to Non-PEG Questionnaire

Statement	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
My child's weight is a problem. (n=127)	8.70%	24.40%	6.30%	36.20%	24.40%
My child doesn't want to gain weight. (n=127)	3.90%	5.50%	22.80%	39.40%	28.30%
My child doesn't eat enough.(n=127)	3.90%	19.70%	6.30%	44.10%	26.00%
CF patients with lung problems need a PEG.(n=125)	0.00%	12.80%	44.80%	29.60%	12.80%
CF patients with no lung problems do not need a PEG.(n=127)	2.40%	15.00%	57.50%	18.90%	6.30%
It would be hard to do sports or other activities with a PEG.(n=127)	4.70%	31.50%	30.70%	30.70%	2.40%
A PEG looks bad.(n=127)	7.80%	38.30%	30.70%	21.30%	1.60%
A PEG would embarrass my child.(n=127)	18.90%	36.20%	24.40%	20.50%	0.00%
A PEG would be painful for my child.(n=126)	7.10%	30.20%	39.70%	23.00%	0.00%
Getting a PEG means my child's CF is getting worse. (n=127)	12.60%	37.00%	21.30%	26.80%	1.60%
My insurance/HMO/Medicaid would pay for the formula used in PEG feedings. (n=125)	2.40%	20.00%	61.60%	8.00%	8.00%
A PEG would help my child grow taller, gain weight, and/or develop puberty.	5.50%	33.90%	44.10%	12.60%	3.90%
A PEG may help my child's lungs. (n=127)	3.10%	21.30%	44.10%	25.00%	5.50%
A PEG may give my child more energy. (n=126)	4.00%	38.90%	38.90%	15.10%	3.20%
If my child was losing weight, I would want him or her to have a PEG. (n=127)	6.30%	41.70%	31.50%	17.30%	3.10%
If my child's appetite got worse, I would want him or her to have a PEG. (n=126)	4.00%	34.10%	34.10%	24.60%	3.20%
I know enough about the good and bad things about PEG tubes. (n=127)	4.70%	15.70%	16.50%	37.80%	25.20%
If my child needed extra nutrition, I would prefer a nasogastric (NG) tube for him or her. (n=127)	3.90%	8.70%	41.70%	24.40%	21.30%

child was losing weight, the parents were more apt to consider PEG placement. However, if nutrition support was indicated, parents were more likely to prefer an NG tube.

PEG vs. Non-PEG

An independent t-test revealed highly significant differences between the responses of people with a PEG and people without a PEG reported in Table 8.

People with a PEG felt that it did not interfere with participation in sports and other activities; look bad; cause embarrassment; or cause pain. However, those people without a PEG thought that a PEG would make it hard to participate in sports and other activities; it would look bad; would cause embarrassment; and would be painful. Those with a PEG did not see placement of the PEG as a sign that their CF was getting worse and felt that the PEG helped them grow. On the other hand, people without a PEG saw PEG placement as

Table 8 PEG vs. Non-PEG Mean Results

Variable	PEG Mean	Non-PEG Mean	2-tailed p values
Age (years)	12.60±6.03 N=35	16.01±13.00 N=202	0.014
Weight (pounds)	75.42±32.07 N=35	89.79±48.79 N=194	0.029
BMI	17.38±2.64 N=30	19.21±3.98 N=159	0.016
Days Hospitalized	15.11±18.78 N=34	7.28±15.36 N=199	0.008
Overall Health Last Year	3.66±1.06 N=35	4.11±0.96 N=200	0.012
Weight Problem	1.44±0.73 N=36	3.30±1.29 N=202	0.000
Sports	3.39±1.29 N=36	2.73±0.96 N=201	0.006
Looks	3.42±1.27 N=36	2.53±0.97 N=202	0.000
Embarrass	3.61±1.18 N=36	2.44±1.06 N=202	0.000
Painful	3.81±1.09 N=36	2.76±0.88 N=201	0.000
Worse	3.36±1.22 N=36	2.58±1.05 N=202	0.000
Grow	1.92±0.94 N=36	2.74±0.87 N=201	0.000

a sign that the CF was getting worse and did not know if the PEG would help them grow.

Covariant analysis was conducted to determine potential confounding factors the differences reported. Age was found to be a possible confounding factor to the responses regarding looks, sports, and the perception of CF getting worse with PEG placement. Gender may have also confounded differences seen in the responses to the statement regarding participation in sports and other activities.

An attitude score based on participants responses to the questionnaire statements revealed that people with a PEG had a more positive attitude toward placement than those without a PEG. A score of 1 was the most positive, a score of 3 was neutral, and a score of 5 was most negative toward PEG placement. The mean score for the PEG questionnaire was 2.35 ± 0.59, and the mean score for the non-PEG questionnaire was 3.12 ± 0.544.

Professional Questionnaire

Questionnaires were returned from professionals working with patients with CF in Idaho, Utah, Colorado, New Mexico, and Arizona. Table 9 describes the demographics of the professionals and how they defined a weight and lung problem.

If a patient was not consuming enough calories orally, 56.5% of the professionals would recommend gastrostomy feedings. Eighty-eight percent of the professionals reported that a gastrostomy would not make it difficult for the patient to participate in sports and other activities. A gastrostomy was not thought to look bad nor be painful for the patient by 73.8% and 65.6% of the professionals. Seventy-one percent of the professionals did not view the gastrostomy placement as an indication that the patient's CF was getting worse. Payment for the formula used in gastrostomy feedings was thought to

Table 9 Professional Characteristics and Definitions

Variable	Percentage
Profession (n=65)	
Pulmonologist	21.5%
Gastroentrologist	6.2%
Nurse	32.3%
Social Worker	4.6%
Dietitian	16.9%
Respiratory Therapist	6.2%
Researcher	1.5%
Other	10.8%
Professional Definitions	
Weight Problem (Expected weight for height) (n=63)	
≤ 95%	1.6%
≤ 90%	25.4%
≤ 85%	30.2%
≤ 80%	22.2%
≤ 75%	20.6%
Lung Problem (Percent expected FEV_1) (n=57)	
≤ 90%	10.5%
≤ 80%	45.6%
≤ 70%	26.3%
≤ 60%	14%
≤ 50%	3.5%

be a problem by 78.5% of the professionals. Gastrostomy feedings were reported to help patients grow, improve their pulmonary status, and give them more energy by 80%, 73.8%, and 93.8% of the professionals. Seventy-three percent of the professionals felt that patients did not know enough about the pros and cons of a gastrostomy. Table 10 shows the mean and median responses to the statements in the professional questionnaire. Table 11 shows the frequencies of responses to the professional questionnare.

Discussion

Demographics for the respondents to the non-PEG questionnaire were similar to

Table 10 Professional Questionnaire Mean/Median Response

Statement	Mean/Median Response
If a patient isn't eating enough, I would recommend gastrostomy feedings.	2.50±1.05 2.00 N=62
A gastrostomy makes it difficult for a patient to participate in sports and other activities.	4.05±0.84 4.00 N=65
A gastrostomy looks bad.	3.75±1.00 4.00 N=65
A gastrostomy is embarrassing for the patient.	2.95±1.03 3.00 N=64
A gastrostomy is painful for the patient.	3.58±0.97 4.00 N=64
Gastrostomy placement means the patient's CF is getting worse.	3.63±0.94 4.00 N=65
Payment for the formula used in gastrostomy feedings is a problem.	2.09±0.90 2.00 N=65
Gastrostomy feedings help patients grow taller, gain weight, or develop puberty.	1.97±0.79 2.00 N=65
Gastrostomy feedings improve pulmonary functions.	2.15±0.85 2.00 N=65
Gastrostomy feedings give the patient more energy.	1.83±0.52 2.00 N=65
Patients know enough about the pros and cons of a gastrostomy.	3.72±0.83 4.00 N=64

Response Key: 1=strongly agree, 2=agree, 3=no opinion, 4=disagree, 5=strongly disagree

that of the National Cystic Fibrosis Patient Registry. Fifty-three percent of the patients registered with the CF Foundation were male, and 51% of the non-PEG questionnaire respondents were male showing a good representation of gender for the CF population (9). The national mean age was 16.4 years, and the mean age for the non-PEG questionnaire respondents was 16 years (9). The PEG questionnaire respondents differed significantly in gender, as 72% were female. This may be due to the fact that more females have a PEG. Females tend to have more severe nutritional complications particularly during adolescence, and, hence, more of them have a PEG. The PEG questionnaire respondents were significantly younger than the non-PEG questionnaire respondents. This once again

may be attributed to more PEGs placed in younger patients. The mean BMI was also significantly lower in the PEG questionnaire respondents indicating these patients had a greater challenge with weight.

Table 11 Frequencies of Responses to Professional Questionnaire

Statement	strongly agree	agree	no opinion	disagree	strongly disagree
If a patient isn't eating enough, I would recommend gastrostomy feedings (n=62)	17.70%	38.70%	19.40%	24.20%	0.00%
A gastrostomy makes it difficult for a patient to participate in sports and other activities. (n=65)	1.50%	6.20%	4.60%	61.50%	26.20%
A gastrostomy looks bad. (n=65)	1.50%	15.40%	9.20%	53.80%	20.00%
A gastrostomy is embarrassing for the patient. (n=64)	0.00%	45.30%	23.40%	21.90%	9.40%
A gastrostomy is painful for the patient. (n=64)	1.60%	17.20%	15.60%	53.10%	12.50%
Gastrostomy placement means the patient's CF is getting worse. (n=65)	0.00%	20.00%	9.20%	58.50%	12.30%
Payment for the formula used in gastrostomy feedings is a problem. (n=65)	23.10%	55.40%	12.30%	7.70%	1.50%
Gastrostomy feedings help patients grow taller, gain weight, or develop puberty. (n=65)	27.70%	52.30%	15.40%	4.60%	0.00%
Gastrostomy feedings improve pulmonary functions. (n=65)	20.00%	53.80%	16.90%	9.20%	0.00%
Gastrostomy feedings give the patient more energy. (n=65)	23.10%	70.80%	6.20%	0.00%	0.00%
Patients know enough about the pros and cons of a gastrostomy. (n=64)	0.00%	12.50%	14.10%	62.50%	10.90%

In order for respondents to remain anonymous and confidentiality maintained, the non-responders were not identified in this study. This may have introduced some bias to the results; however, the demographics of responders and nonresponders were similar. The

nonresponders may not be as compliant as the responders, and compliance largely influences the outcome of a PEG. Further research of compliance and success of PEG placement needs to be conducted.

The responses to the PEG questionnaire showed that patients with a PEG were positive about PEG placement. Inadequate weight gain or maintenance and deficient oral consumption of calories influenced the decision of whether or not to place a PEG. The responses to the non-PEG questionnaire revealed that patients without a PEG were apathetic towards PEG placement and more concerned that the PEG would interfere with sports, be embarrassing, look bad, and be painful.

The lack of knowledge expressed on the responses to the non-PEG questionnaire and professionals acknowledging a knowledge deficit in patients understanding of PEG placement indicates a need for further patient education. Insights from expert nurses in long-term gastrostomy placement talked about the importance of parent learning in making the decision to place a PEG (10). Providing parents and patients with information about the benefits and costs of a PEG prior to placement time provides tools to make the decision regarding placement. The expert nurses emphasized the need for anticipatory planning in making the decision to place a PEG and adjusting to life with a PEG. An important strategy in this approach was to have experienced parents talk with parents who might be considering PEG placement. Since the patients with a PEG have found that a PEG does not look bad, is not embarrassing, does not interfere with sports, and is not painful, they could help market the positive aspects of a PEG. A list of patients with a PEG who consented to talk with patients considering a PEG placement could be developed, and the

multi-disciplinary team would make appropriate referrals. Developing a video of patients with a PEG participating in various activities and modeling the PEG could be another way to share the gastrostomy experience. Education needs to be focused on the positive benefits of PEG placement such as improved growth and increased energy. Misconceptions about a PEG interfering with sports and other activities and a PEG being painful need to be cleared up.

This study has shown that PEG placement can be a positive experience and that those patients without a PEG lack in knowledge of the benefits of a PEG. Further education of patients with CF about PEG placement would be very beneficial.

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CHAPTER IV

GENERAL CONCLUSION

PEG placement improves weight and height; however, if pulmonary function is already compromised, PEG placement may contribute to worsening lung function. Earlier placement rather than later improves nutrition status, yet there are barriers toward placement.

People with CF with a PEG have a positive attitude and do not feel that it is embarrassing, painful, or looks bad. Parents and /or patients with CF without a PEG lack knowledge about PEG placement and have no opinion regarding various aspects of a PEG.

Patients with CF and their families need more education regarding the cost and benefits of PEG placement. Discussion of PEG placement needs to be done as part of the anticipatory guideline CFF recommendations to prevent unnecessary malnutrition.

APPENDIXES

Dear Friends,

We need your help in completing the surveys enclosed in this letter. Sometimes people with CF cannot eat enough food to meet their high energy needs. They may have problems gaining weight, not being hungry, or not being able to eat enough. When this happens, the person needs to be fed in another way. We are trying to find out what people with cystic fibrosis and/or their families think about the use of feeding tubes.

These surveys are being mailed to patients seen at:
Intermountain Cystic Fibrosis Center--
Primary Children's Medical Center (Salt Lake City, Utah)
University of Utah Medical Center (Salt Lake City, Utah)
CF Satellite Centers (Pocatello and Boise, Idaho)

The surveys should take no more than 10 minutes each to complete. All information collected from the surveys will remain strictly confidential. You do not need to put your name on the survey. No individual will be identified. Your return of the completed survey serves as consent to participate in the study. Please fill out the green survey and return in the enclosed envelope. If your child is between the ages of 10 to 18 years, please explain the study as needed and give him or her the letter with the pink survey. You will find in this packet the following:

A letter for a person with CF between ages 10 to 18 years
A pink survey for:
A person with CF at least 10 years old
A green survey for:
The parent(s) or guardian(s) of a person with CF under the age of 18 years
A yellow sheet describing a certain type of feeding tube
Please read the yellow sheet before you complete the survey.
A self-addressed stamped envelope

If you have any questions concerning the study, please contact Katie McDonald, MS RD or Sarah Gunnell, RD at (801) 588-3898. Thank you for your time and interest in improving the quality of life of people with cystic fibrosis.

Sincerely,

Katie McDonald, M.S. R.D.
Clinical Dietitian
Primary Children's Medical Center

Sarah Gunnell, R. D.
Graduate Student
Utah State University

Dear Friends,

We need your help in completing the surveys enclosed in this letter. We are trying to find out what people with cystic fibrosis who have a gastrostomy and/or their families think about it.

These surveys are being mailed to patients seen at:
Intermountain Cystic Fibrosis Center--
Primary Children's Medical Center (Salt Lake City, Utah)
University of Utah Medical Center (Salt Lake City, Utah)
CF Satellite Centers (Pocatello and Boise, Idaho)

The surveys should take no more than 10 minutes each to complete. All information collected from the surveys will remain strictly confidential. You do not need to put your name on the survey. No individual will be identified. Your return of the completed survey serves as consent to participate in the study. Please fill out the blue survey and return in the enclosed envelope. If your child is between the ages 10 to 18 years, please explain the study as needed and give him or her the letter with the tan survey. You will find in this packet the following:

A letter for a person with CF between ages 10 to 18 years
A tan survey for:
A person with CF at least 10 years old who has a gastrostomy feeding tube
A blue survey for:
The parent(s) or guardian(s) of a person with CF under the age of 18 years who has a gastrostomy feeding tube
A yellow sheet describing a certain type of feeding tube
Please read the yellow sheet before you complete the survey.
A self-addressed stamped envelope

If you have any questions concerning the study, please contact Katie McDonald, MS RD or Sarah Gunnell, RD at (801) 588-3898. Thank you for your time and interest in improving the quality of life of people with cystic fibrosis.

Sincerely,

Katie McDonald, M.S. R.D.
Clinical Dietitian
Primary Children's Medical Center

Sarah Gunnell, R. D.
Graduate Student
Utah State University

Different Ways of Providing Nutrition

People with cystic fibrosis may not always be able to eat enough food for normal growth. When this happens, they may choose to provide nutrition through a feeding tube. One type of feeding tube is called a nasogastric (NG) feeding tube. This is placed through the nose into the stomach. Another type of tube is a percutaneous endoscopic gastrostomy, better known as PEG. It is placed directly into the stomach through the skin. The picture below shows what a gastrostomy looks like. Once the feeding tube is placed, the person is able to receive food through it. The food is in a liquid form and contains protein, carbohydrates, fats, vitamins, and minerals.

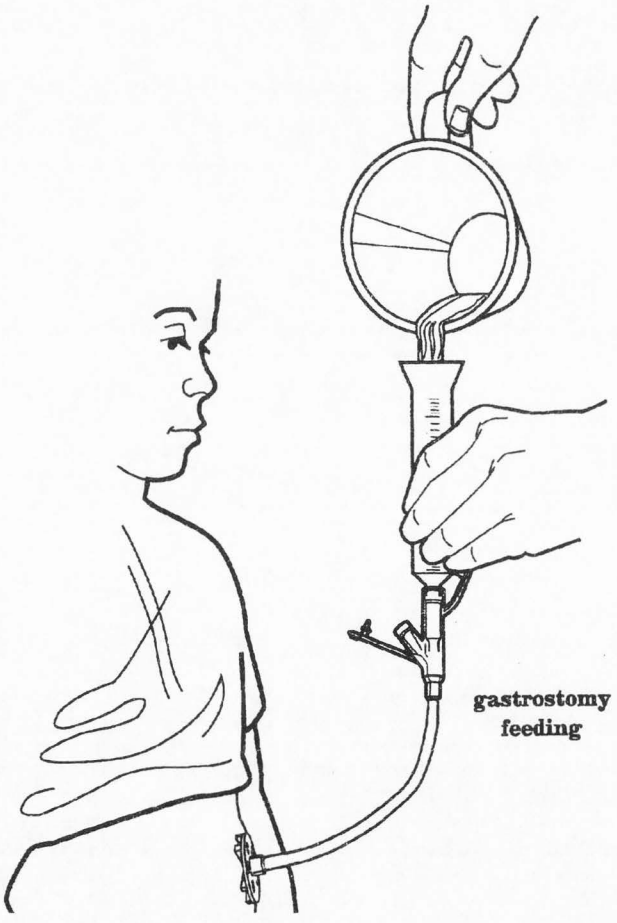

Figure 1 Gastrostomy Feeding

Dear CF Friend,

Some children with cystic fibrosis (CF) gain weight slowly. Sometimes children with CF are smaller than their friends. A feeding tube is one way of helping a person with CF to gain weight and grow taller. You may have a feeding tube or you may know someone who does.

We would like to know what you think about feeding tubes. We are sending this letter to all of the children with CF older than 10 years who are seen in the CF outpatient clinic at Primary Children's Medical Center. Your answers to these questions will help the CF center understand what people with CF think about gaining weight and using feeding tubes.

Your parents can help you if there are parts of the questions you don't understand. But, we want to know what YOU think about the questions, not what your parents think. They have their own set of questions to answer.
You don't have to answer these questions if you don't want to. You can throw these papers away.

If you do answer these questions, do not write your name on the papers. We don't want to know which child with CF is answering the questions. We will count the number of different answers to each question and then tell what the numbers were. For example, we will say, " For question XYZ, 50 people said, 'No' and 20 people said, 'Yes.'"

If you answer the questions and send the sheet back to us, your answers will be used in our study. Give these papers back to your parents when you are done. They will send your answer sheet and their answer sheet back to us.

Thanks for reading this letter. We hope you will answer the questions so that we can learn more about what children with CF think about gaining weight and using feeding tubes.

Sincerely,

Katie McDonald, M.S. R.D.
Clinical Dietitian
Primary Children's Medical Center

Sarah Gunnell, R. D.
Graduate Student
Utah State University

Attitudes Toward Percutaneous Endoscopic Gastrostomy (PEG) Questionnaire for People Who DO NOT Have PEG

Age_____ Weight_____ Height_____ Male_____ Female_____ Zip Code _____
Date____/____/____

Number of days hospitalized in last year _____

Physician or cystic fibrosis team has recommended the placement of a PEG. Yes____ No____

What is your overall health in the last year? ___very poor ___poor ___okay ___good ___very good

What is your level of physical activity in the last year compared to other people your age?
____much less active ___less active ____about the same ____more active ___much more active

---

Please circle the number below each statement that best expresses your opinion of the statement.

1. My weight is a problem.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
2. I don't want to gain weight.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
3. My family or friends think I don't eat enough.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
4. CF patients with lung problems need a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
5. CF patients with no lung problems do not need a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
6. It would be hard to do sports or other activities with a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
7. A PEG looks bad.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
8. A PEG would embarrass me.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
9. A PEG would hurt.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
10. Getting a PEG means my CF is getting worse.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
11. My insurance/HMO/Medicaid would pay for the formula used in PEG feedings.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
12. A PEG would help me grow taller, gain weight, or develop puberty.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
13. A PEG may help my lungs.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
14. A PEG may give me more energy.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
15. If I was losing weight, I would want a PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
16. If my appetite got worse, I would want a PEG .
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
17. I know enough about the good and bad things about PEG tubes.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
18. If I needed extra nutrition, I would prefer a nasogastric (NG) tube.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

Attitudes Toward Percutaneous Endoscopic Gastrostomy (PEG) Questionnaire for Parents of People Who DO NOT Have PEG

Patient Information
Age_____ Weight_____ Height_____ Male_____ Female_____ Zip Code _____
Date____/____/____

Number of days hospitalized in last year _____
Physician or cystic fibrosis team has recommended the placement of a PEG. Yes____ No____
What is your child's overall health in the last year? ___very poor ___poor ___okay ___good ___very good
What is your child's level of physical activity in the last year compared to other people your age?
____much less active ___less active ____about the same ____more active ___much more active

---

Please circle the number below each statement that best expresses your opinion of the statement.

1. My child's weight is a problem.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
2. My child doesn't want to gain weight.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
3. My child doesn't eat enough.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
4. CF patients with lung problems need a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
5. CF patients with no lung problems do not need a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
6. It would be hard to do sports or other activities with a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
7. A PEG looks bad.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
8. A PEG would embarrass my child.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
9. A PEG would be painful for my child.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
10. Getting a PEG means my child's CF is getting worse.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
11. My insurance/HMO/Medicaid would pay for the formula used in PEG feedings.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
12. A PEG would help my child grow taller, gain weight, and/or develop puberty.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
13. A PEG may help my child's lungs.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
14. A PEG may give my child more energy.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
15. If my child was losing weight, I would want him or her to have a PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
16. If my child's appetite got worse, I would want him or her to have a PEG .
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
17. I know enough about the good and bad things about PEG tubes.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree
18. If my child needed extra nutrition, I would prefer a nasogastric (NG) tube for him or her.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

Attitudes Toward Percutaneous Endoscopic Gastrostomy (PEG)
Questionnaire for People Who Have PEG

Age_____ Weight_____ Height_____ Male_____ Female_____ Zip Code _____ Date ____/____/____

Number days hospitalized in last year_____

When was your PEG placed? _____month _____ year

What is your overall health in the last year? ___very poor ___poor ___okay ___good ___very good

What is your level of activity in the last year compared to other people your age?
____much less active ___less active ____about the same ____more active ___much more active

---

Please circle the number below each statement that best expresses your opinion of the statement.

1. When my PEG tube was placed, I had healthy lungs.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

2. My weight was a problem when the PEG was placed.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

3. I ate enough before my PEG was placed.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

4. I have gained weight with my PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

5. I thought that getting a PEG meant my CF was getting worse.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

6. My PEG makes it hard to do sports or other activities.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

7. I think my PEG looks bad.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

8. I would be embarrassed if my friends knew I had a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

9. My PEG hurts.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

10. My family has trouble buying the formula.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

11. The PEG has helped me grow taller, gain weight, and/or develop puberty.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

12. The PEG has helped my lungs.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

13. I have more energy with my PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

14. I am healthier now after the PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

15. If I could do it over again, I would NOT have a PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

Attitudes Toward Percutaneous Endoscopic Gastrostomy (PEG)
Questionnaire for Parents of People Who Have PEG

Patient Information

Age_____ Weight_____ Height_____ Male_____ Female_____ Zip Code _____ Date ____/____/____

Number of days hospitalized in last year_____

When was your child's PEG placed? _____month _____ year

What is your child's overall health in the last year? ___very poor ___poor ___okay ___good ___very good

What is your child's level of activity in the last year compared to other people his or her age?

____much less active ___less active ____about the same ____more active ___much more active

---

Please circle the number below each statement that best expresses your opinion of the statement.

1. When my child's PEG tube was placed, he or she had healthy lungs.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

2. My child's weight was a problem when the PEG was placed.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

3. My child ate enough before his or her PEG was placed.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

4. My child has gained weight with his or her PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

5. I thought that getting a PEG meant my child's CF was getting worse.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

6. My child's PEG makes it hard for him or her to do sports or other activities.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

7. My child's PEG looks bad.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

8. My child would be embarrassed if his or her friends knew he or she had a PEG.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

9. My child's PEG is painful.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

10. We have difficulty affording the formula.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

11. The PEG has helped my child grow taller, gain weight, and/or develop puberty.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

12. The PEG has helped my child's lungs.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

13. My child has more energy with his or her PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

14. My child is healthier now after the PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

15. If I could do it over again, my child would NOT have a PEG.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

July 21, 2000

Dear Cystic Fibrosis Team Member:

You are invited to complete a questionnaire regarding the attitudes of professionals toward gastrostomies. This past spring questionnaires were sent to measure the attitudes of people with CF and/or their families toward gastrostomy placement in the mountain west region. The Mountain West Consortium identified the need to assess the attitudes of professionals toward gastrostomy placement. As a follow-up, you are invited to complete the enclosed questionnaire for professionals regarding gastrostomy placement. All responses will remain strictly confidential. Names will not be used for this study, but we are requesting you to list your professional discipline. Only Nedra K. Christensen, Priniciple Investigator for this study, Sarah Gunnell, a Utah State University graduate student, and Katie McDonald, from Intermountain Cystic Fibrosis Clinic will have access to this data. The questionnaires will be kept in a locked file cabinet in Dr. Christensen's office. Please return the completed questionnaire in the enclosed envelope. If you have any questions, please contact Katie McDonald or Sarah Gunnell at (801) 588-3898 or Nedra K. Christensen (801) 484-9374. Thank you for your participation and willingness to help improve nutritional therapy in people with CF.

Sincerely,

Nedra K. Christensen PhD, RD RD	Sarah Gunnell, RD	Katie McDonald MS,
Assistant Professor	Graduate Student	Clinical Dietitian
Utah State University Medical	Utah State University	Primary Children's
Logan, UT 84322-8700	Logan, UT 84322-8700	Center

Attitudes Toward Gastrostomy Placement in People with Cystic Fibrosis Questionnaire for Professionals

Date ___/___/___

Please mark your profession.

Pulmonologist ____ *Gastroentrologist* ____ *Nurse* ____ *Social Worker* ____ *Dietitian* ____
Respiratory Therapist ____ *Researcher* ____ *Other* _____ *please specify*_____

How many patients have you recommended gastrostomy placement to within the past year? _____

Please describe the current criteria for placing a gastrostomy as you understand it.

Please circle the number below each statement that best expresses your opinion of the statement.

1. I would define a weight problem as: (in terms of expected weight for height).
   1 ≤ 95% 2 ≤ 90% 3 ≤ 85% 4 ≤ 80% 5 ≤ 75%

2. What percentage of patients don't want to gain weight?
   1 =5-10% 2 =11-20% 3 = 30-50% 4 = 60-75% 5 = 90-100%

3. Lung problems would be described as FEV_1 of: (expressed in percent expected).
   1 ≤90% 2 ≤80% 3 ≤70% 4 ≤60% 5 ≤50%

4. If a patient isn't eating enough, I would recommend gastrostomy feedings.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

5. A gastrostomy makes it difficult for a patient to participate in sports and other activities.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

6. A gastrostomy looks bad.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

7. A gastrostomy is embarrassing for the patient.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

8. A gastrostomy is painful for the patient.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

9. Gastrostomy placement means the patient's CF is getting worse.
   1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

10. Payment for the formula used in gastrostomy feedings is a problem.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

11. Gastrostomy feedings help patients grow taller, gain weight, or develop puberty.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

12. Gastrostomy feedings improve pulmonary functions.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

13. Gastrostomy feedings give the patient more energy.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree

14. Patients know enough about the pros and cons of a gastrostomy.
    1 =strongly agree 2 =agree 3 = no opinion 4 = disagree 5 =strongly disagree